

ONLINE SUPPLEMENTARY DATA

Survey Questions

Good Days Fast survey

Q1. Are you:

- Male
- Female

Q2. How old are you?

Q3. What is your current working status?

- Employed full-time (30+ hours per week)
- Employed part-time (Less than 30 hours per week)
- Self-employed
- Retired
- Home-maker/Housewife
- Unemployed/receiving benefits
- Full time education
- Other

Q4. What is your current marital status?

- Married
- Living with partner
- Single (divorced/separated)
- Single (widowed)
- Single (never married)

Q5. Which of the following medical conditions do you currently have?

- Heart disease
- High blood pressure
- Osteoporosis
- Rheumatoid Arthritis
- Osteoarthritis
- Asthma
- None of the above

Q6. Approximately how long ago were you first diagnosed with Rheumatoid Arthritis?

- Less than 6 months

- More than 6 months
- Over a year

Q7. How would you describe the severity of your Rheumatoid Arthritis?

- Mild
- Moderate
- Severe

Q8. How has RA affected your participation in the following activities? Which activities has RA stopped you from doing at all and which do you find painful or more difficult to do?

	RA pain has stopped me from doing this activity at all	Always painful /more difficult	Sometimes painful / more difficult	RA has no effect on this activity	Not applicable	Decline
Driving						
Cooking						
Shopping for groceries / clothes						
Gardening						
Playing with children, grandchildren or young relatives						
Beauty regime (putting on make-up, styling hair etc.)						
Sleeping						
Going out to restaurants, bars, cinema						
Housework						
Doing your favourite hobby						
Keeping fit/sport						
Entertaining at home						

Being intimate with partner/husband						
Physiotherapy or other health-related exercises						
Administering your own medication						
Spending time enjoying outdoor activities eg. walks in the country						

Q9. Thinking now about the Christmas/Holiday season, which of the following activities do you find difficult to do as a result of having RA?

	RA pain has stopped me from doing this activity at all	Always painful / more difficult	Sometimes painful / more difficult	RA has no effect on this activity	Not applicable
Wrapping presents					
Writing Christmas cards					
Preparing festive food					
Attending celebrations and parties					
Going shopping for Christmas presents					
Spending time with family and friends					
Going to church or religious ceremonies					

Q10. Moving on to your working life, which of the following have you had to do as a result of having RA?

- Stop working altogether/Retire early
- Change the kind of job you do (eg. office work vs working outdoors)
- Take a pay cut
- Resist from promotion or career advancement

- Work part-time instead of full-time
- Take more than 10 days sick off work in an average year
- Routinely attend medical appointments during work time
- Have your workstation or working environment modified
- Inform your employer or colleagues about your condition
- None of the above

Q11. How often are you less productive at work than you would like to be due to RA?

- Always
- Often
- Sometimes
- Rarely
- Never

Q12. On the next screen are a series of statements that other RA patients have said about their lifestyle. Please indicate the extent to which you agree or disagree with each statement.

	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly	Decline
My friends and family don't really understand the pain or fatigue I suffer						
I find it very difficult to do 'normal' everyday activities due to RA						
Having RA has really affected my closest relationships for the worse						
I often worry about losing my independence when I'm older due to RA						
I don't enjoy family events like Christmas and birthdays as much as I used to because of RA						

I feel as if RA has robbed me of my happiness						
I'm constantly looking for new ideas that can help with my pain						
It's often difficult for me to do something spontaneous these days due to RA						
RA has given me a new perspective on life and I am thankful for days/time when I am well						
I frequently find my RA emotionally distressing						
I find it very difficult to explain my sexual needs to my partner/husband						

Q13. And here are some more statements that other RA patients have said about their lifestyle. Again, please indicate the extent to which you agree or disagree with each statement.

	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
I often feel that I am treated as though I am disabled					
Because of my condition people think of me as elderly and frail					
People think I am helpless because of my RA					
I conceal pain from friends and family					

during social occasions or day to day living					
I can't make plans due to uncertainty around pain and mobility and fatigue					
I end up buying practical clothes or shoes rather than the stylish ones I really wanted					
I have had to give up the foods I most enjoy eating					
RA forces me to compromise on choice of holiday destination					
I feel isolated from my friends and family because of my RA					
RA often makes me feel awkward in social situations					
I feel depressed a lot of the time because of my RA					

Q14. Are you currently taking pain-relief medication to treat your Rheumatoid Arthritis?

- Yes
- No
- Don't know
- Declined

Q15. Do you experience pain on a daily basis?

- Yes
- No
- Don't know
- Declined

**Q16. How would you describe your experiences when visiting your doctor / physician?
How often do you do or feel the following? (Click as many as apply)**

	Always	Often	Sometimes	Rarely	Never
Mention the pain you experience					
Describe the type of pain you experience and how often you experience it					
Accept advice given					
Challenge the advice you get					
Feel rushed and unable to talk about everything you want to					
Feel like you are complaining when you discuss your symptoms or side-effects					
Feel too shy to talk about how much pain you are really in					
Intend to talk about pain control, but not get around to it					
Discuss the level of tiredness/fatigue that you feel					

Q17. Would you describe your relationship with your doctor/physician as a partnership, where you are working together to manage your condition?

- Yes
- No
- Don't know

Q18. Would you like to have a partnership like this with your doctor / physician?

- Yes
- No
- Don't know

Q19. Would you describe your relationship with your specialist nurse as a partnership, where you are working together to manage your condition?

- Yes
- No
- Don't know

Q20. Would you like to have a partnership like this with your nurse?

- Yes

- No
- Don't know

Q21. Which of the following defines a good day for you? (Click the top 3 options which apply to you)

- Having a day free of pain
- Experiencing pain relief quickly
- Being able to be intimate with my partner
- Being able to go to work
- Not feeling self-conscious because of arthritis
- Being able to do everyday things easily such as taking a shower, getting dressed etc
- Being free of fatigue, having energy
- No morning stiffness
- Being able to take care of/play with my children
- Being able to cook for my friends / family
- Being able to attend church / religious ceremonies
- Being able to participate in outdoor activities (walking, gardening etc)
- Other, please specify:

Q22. Can you describe in a few words what a good day is like for you?

Q23. How often does your RA make you feel less self-confident in each of the following situations? (As before, for each situation, please click whether you feel less self-confident often, sometimes, rarely or never)

	Always	Often	Sometimes	Rarely	Never	N/A Declined
At work						
When meeting new people						
With friends						
In large social groups (eg. at parties or family gatherings)						
Your sex life						

Q24. To what extent did RA play a role in your divorce/separation?

- It was the main reason

- It played a big part but wasn't the main reason
- It had some role in the decision
- It had no impact at all
- Declined

Q25. Do you think having RA makes it more difficult to find a partner?

- Strongly agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

Q26 To what extent do you agree that the government understands and supports your condition?

- Strongly agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

Getting to Your Destination Faster (GTYDF) survey

Q1. Are you:

- Male
- Female

Q2. Approximately how many years ago were you first diagnosed with rheumatoid arthritis?

Q3. How would you describe the severity of your rheumatoid arthritis?

- Moderate
- Mild
- Severe

Q4. What is your current working status?

- Employed full-time (30+ hours per week)
- Employed part-time (less than 30 hours per week)

- Unemployed / receiving benefits
- Retired
- Home-maker / Housewife / Househusband
- Self-employed
- Full-time education
- Other
- Decline to answer

Q5. Has your rheumatoid arthritis negatively impacted your employment status (e.g. stopped working altogether, moved from full-time to part-time work, forced you to change your job or job role)?

- Yes, rheumatoid arthritis has negatively affected my employment status
- No, rheumatoid arthritis has not negatively affected my employment status

Q6. What is your current marital status?

- Married
- Single (divorced / separated)
- Living with partner
- Single (never married)
- Civil partnership
- Single (widowed)
- In a relationship
- Decline to answer

Q7. Has your rheumatoid arthritis negatively affected your relationship (e.g. rheumatoid arthritis contributed to my divorce / separation, rheumatoid arthritis makes it difficult to find a new partner, RA contributes to arguments/tension with my partner)?

- No, rheumatoid arthritis has no negative affect or hasn't negatively affected my relationship status
- Yes, rheumatoid arthritis negatively affects or has negatively affected my relationship status
- Decline to answer

Q8. Are you currently taking medication as a result of your rheumatoid arthritis?

- Yes

- No

Q9. What medication(s) are you currently taking for your rheumatoid arthritis?

- Painkillers like ibuprofen and naproxen (eg. medicine for symptomatic relief)
- Methotrexate, sulphasalazine, leflunomide, hydroxychloroquine (eg. DMARDs)
- Anti-TNF (eg, biologic DMARDs), rituxan / MabThera (rituximab), Orencia (abatacept), Actemra / RoActemra (tocilizumab), Remicade (infliximab), Cimzia (certolizumab pegol), Humira (adalimumab), Enbrel (etanercept)
- Other
- I don't know what medicine(s) I am currently taking

Q10. Thinking about your rheumatoid arthritis, over the years, in total, how many different medicines do you think you have taken?

- 1 - 2
- 3 - 4
- 5 - 6
- 7 – 10
- Over 10

Q11. Thinking about the medicines taken to relieve your rheumatoid arthritis signs and symptoms (i.e. joint stiffness, joint swelling, fatigue, IN ADDITION TO pain relief), how quickly do you think they worked?

- Within 3 months
- 3 – 6 months
- Over 6 months

Q12. Let's say that you were given a medicine for your rheumatoid arthritis signs and symptoms (in addition to pain relief), how quickly would you EXPECT to feel an improvement in your signs and symptoms associated with rheumatoid arthritis?

- Within 3 months
- 3 – 6 months
- Over 6 months

Q13. Let's say that you were given a medicine for your rheumatoid arthritis signs and symptoms (in addition to pain relief), how quickly would you WANT to feel an improvement in your signs and symptoms associated with rheumatoid arthritis?

- Within 3 months

- 3 – 6 months
- Over 6 months

Q14. Let’s say you start a new medicine to treat your rheumatoid arthritis signs and symptoms (in addition to pain relief), if it’s not working, how long do you think you would wait before speaking to your doctor or nurse?

- 1 week
- 2 weeks
- 3 weeks
- 4 weeks
- 6 weeks
- 8 weeks
- 12 weeks

Q15. Think about what you would expect a rheumatoid arthritis medicine to deliver and please RANK the following items from the list below (top being what you most want from a rheumatoid arthritis medicine and bottom being what you find least important)

	1	2	3	4
Pain relief				
Fatigue relief				
Improved work / home productivity (increased interaction with family and friends, greater ease in house tasks)				
Reduced joint stiffness				

Q16. In relation to rheumatoid arthritis, have you heard of any of the following medical terms?

	Yes	No
CD AI		
ACR Score		
HIAQ Score		

HRQoL		
SDAI		
DAS		
DAS28		
Swollen joint count		
RAPID 3		

Q17. In relation to rheumatoid arthritis, are you familiar with any of the following measurements?

	Yes	No
Improvements in my pain		
Low disease activity		
Improvements in my activity and productivity levels		
Sleeping through the night and feeling refreshed in the morning		
Improvements in the signs and symptoms of my rheumatoid arthritis		
Feeling more positive and confident in myself		

Q18. Let's say that you have started taking a medicine for your rheumatoid arthritis. Would you set yourself PERSONAL or SOCIAL goals / targets when you first start this new medicine?

- Yes
- No

Q19. Let's say that you have started taking a medicine for your rheumatoid arthritis. Do you set yourself TREATMENT goals or targets when you first start a new treatment?

- Yes
- No

Q20. Can you describe in a few words what personal or social and treatment goals / targets you would like to set for yourself?

Q21. Thinking about your rheumatoid arthritis, below are a series of statements, please indicate which of the following statements you agree with:

	I agree	I do not agree
I feel anxious about initiating a new medicine because I'm unsure whether it will help reduce the signs and symptoms of my rheumatoid arthritis		
I feel less anxious about my medicine once I know it is helping to reduce the signs and symptoms of my rheumatoid arthritis		
Knowing that my medicine is working makes me feel more self-confident		
I want a treatment that works quickly		
I think setting myself personal and social goals/targets would be of benefit as I can then assess whether my treatment is working or not in a simple to understand way		
I would find it helpful if my doctor / nurse provided examples of personal social goals / targets I should be setting to assess my condition and treatment		
A treatment that works is a treatment that gets me to my personal and social goals / targets first		
It's important to me to discuss my course of treatment with my healthcare professional		
Setting personal and social goals / targets (eg. to be able to do the washing up, ride my bike, walk further) would allow me to assess whether my treatment is working		
If I set myself personal and social goals / targets and achieved them I would feel positive		
I would describe having a good day as a day with no pain or discomfort and energy filled		
Having a good day would be a great goal / target for me		

Q22. What do you feel is your biggest obstacle to controlling your rheumatoid arthritis symptoms?

- Finding the right treatment option
- Lack of education and understanding of my disease
- Lack of assistance from my physician
- Lack of personal resolve
- Other (*please list*)

Q23. Below are a series of statements that other rheumatoid arthritis patients have said about their activity levels and work/home productivity. Please indicate which of following statements you agree with:

	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
It is unrealistic to expect an improvement in my activity levels and work / home productivity by 3 months of initiating a new treatment					
I want to see an improvement in my activity levels and work / home productivity by 3 months following initiation of a new medicine					
I want to be more productive at work and at home					
Being more active and able to participate in everyday activities (eg. gardening, cooking) is a priority for me					

Q24. Below are a series of statements about treatment and objectives to help patients with rheumatoid arthritis manage their disease. From a patient perspective, please indicate which of following statements you agree with:

	I agree	I do not agree

Establishing personal treatment targets for my rheumatoid arthritis will have a positive impact on my disease management		
Personal disease treatment targets for managing my rheumatoid arthritis are of no importance to me		
I have heard of the treat-to-target approach in rheumatoid arthritis disease management		
My healthcare professional currently manages my rheumatoid arthritis intensively with strict goals and timeframes in place		
When I visit my healthcare professional I have in-depth discussions about how my rheumatoid arthritis is managed		
I would like to have more control over how my rheumatoid arthritis is managed		
I would like to have more in-depth discussions with my healthcare professional about how my rheumatoid arthritis is managed		
My healthcare professional and I make shared decisions about how best to manage my rheumatoid arthritis		

Q25. Has your healthcare professional discussed treating your rheumatoid arthritis with an approach that achieves PERSONAL or SOCIAL goals / targets (often referred to within the medical community as treat-to-target)?

- Yes
- No

Q26. In your opinion, as a patient, what does a targeted approach to disease management mean to you?

- Setting personal lifestyle and treatment goals, and monitoring disease progress to achieve these goals
- Developing and adhering to a strict treatment plan
- Stronger pain relief medication
- More appointments and longer time with the healthcare professional
- Higher dosage of medication
- I do not know
- Other (*please specify*)

ONLINE SUPPLEMENTARY TABLES

Supplementary Table 1. Patient characteristics/demographics of each survey.

Characteristics	Good Days Fast	Getting to Your Destination Faster	
No. of patients	1958	1829	
No. of patients per country			
USA	300	303	
Canada	155	[not included in this survey]	
UK	300	306	
France	301	306	
Germany	300	304	
Italy	302	306	
Spain	300	304	
Gender, n (%)	Female (100.0)	Female: 1242 (67.9)	Male: 587 (32.1)
Age group, n (%)		<u>Female</u>	<u>Male</u>
25-35	401 (20.5)	25-34: 164 (72.2)	63 (27.8)
36-45	533 (27.2)	35-44: 257 (70.8)	106 (29.2)
46-55	628 (32.1)	45-54: 425 (68.5)	195 (31.5)
56-65	396 (20.2)	55-65: 396 (64.0)	223 (36.0)
Time since RA diagnosis, n (%)			
≥6 months	496 (25.3)	[not available]	
≥1 year	1462 (74.7)		
Disease activity, n (%)^a			
mild	606 (30.9)	600 (32.8)	
moderate	1111 (56.7)	985 (53.9)	
severe	241 (12.3)	244 (13.3)	
Relationship status, n (%)			
Married/living with partner	1347 (68.8)	1045 (57.1) ^b	
Single	611 (31.2)		
Divorced/separated	295 (15.1)	208 (11.4)	
Never married	233 (11.9)	189 (10.3)	
Widowed	83 (4.2)	57 (3.1)	

^aPatient-defined; ^bdoes not include: living with partner (190/10.4%), civil partnership (76/4.2%), in a relationship (55/3.0%)

Supplementary Table 2. Examples of personal, social and treatment goals set by patients.

Q. Can you describe in a few words what personal, social or treatment goals you would like to set for yourself?

Being able to walk for longer distances without pain

Being pain free and able to play more physical games with my child

Feel less tired so I can do things with my children

Have less pain at night so I can sleep through and feel refreshed and also be able to gently restart doing things at the gym

Feeling like going out more, sleeping better, less depressed

I would love to be able to sleep through the whole night without waking in pain

Play with grandchildren, walking, climbing stairs, sleep through the night

Pain relief and to regain the ability to grip tools (particularly garden tools) and to be able to open such everyday items as jam/sauce jars

Would like to be able to hold things without pain and dropping dishes, use my computer without pain, hold books, manage pain and be able to relax at night, don't want side effects and would like to reduce fatigue

A tablet that does not upset my liver function and my stomach

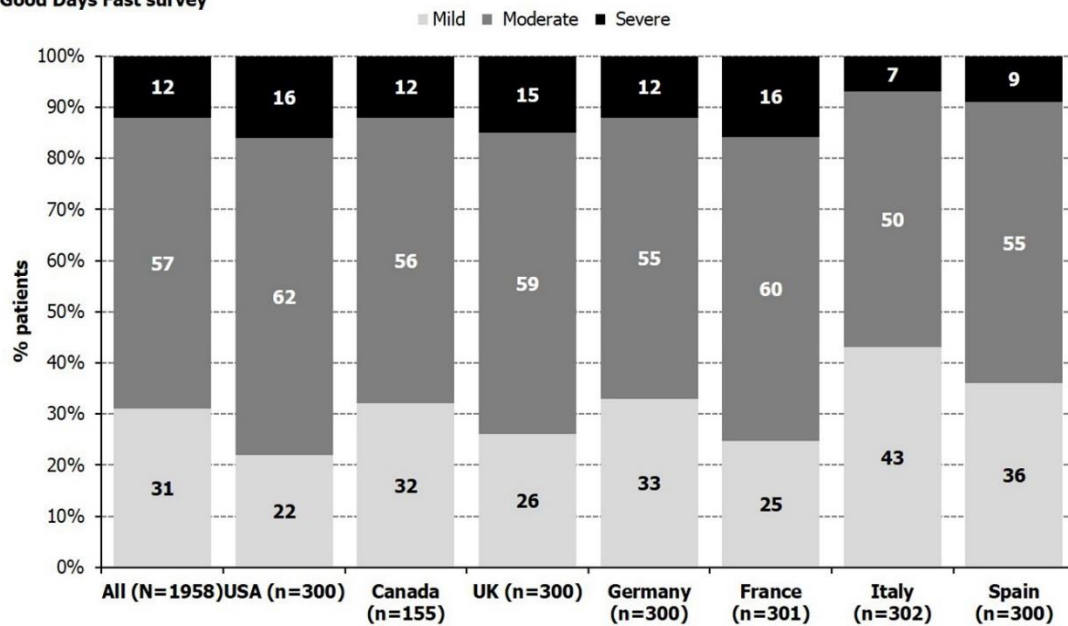
Supplementary Table 3. Patients' assessment of pain by country (Good Days Fast survey; N=1958).

	% patients (95% confidence interval)						
	UK	France	Germany	Italy	Spain	USA	Canada
Feel like complaining when discussing symptoms	77 (72, 82)	80 (76, 85)	64 (59, 70)	73 (68, 78)	71 (66, 76)	71 (66, 77)	72 (65, 79)
Feel too shy to talk about how much pain is experienced	58 (53, 64)	58 (53, 64)	55 (49, 61)	64 (59, 69)	58 (52, 64)	40 (35, 46)	48 (41, 56)
Intend to talk about pain control, but never get round to it	52 (47, 58)	58 (52, 63)	54 (48, 60)	60 (54, 65)	60 (55, 66)	42 (36, 48)	50 (48, 57)
Constantly looking for new ideas to help with pain	64 (59, 69)	73 (68, 78)	68 (63, 73)	61 (56, 67)	70 (65, 76)	68 (62, 73)	68 (60, 75)
Mention the pain experienced	86 (82, 90)	87 (83, 90)	77 (73, 82)	91 (86, 94)	93 (90, 96)	91 (88, 94)	86 (80, 91)
Discuss the level of tiredness/fatigue	73 (68, 78)	82 (78, 87)	72 (67, 77)	88 (84, 91)	87 (84, 91)	82 (78, 86)	77 (70, 83)
Experience pain on a daily basis	76 (71, 81)	64 (58, 69)	58 (52, 63)	41 (36, 47)	51 (46, 57)	85 (81, 89)	72 (65, 79)
Currently take pain relief medication	80 (75, 84)	78 (73, 82)	70 (65, 75)	63 (58, 69)	79 (74, 84)	82 (78, 86)	74 (67, 81)

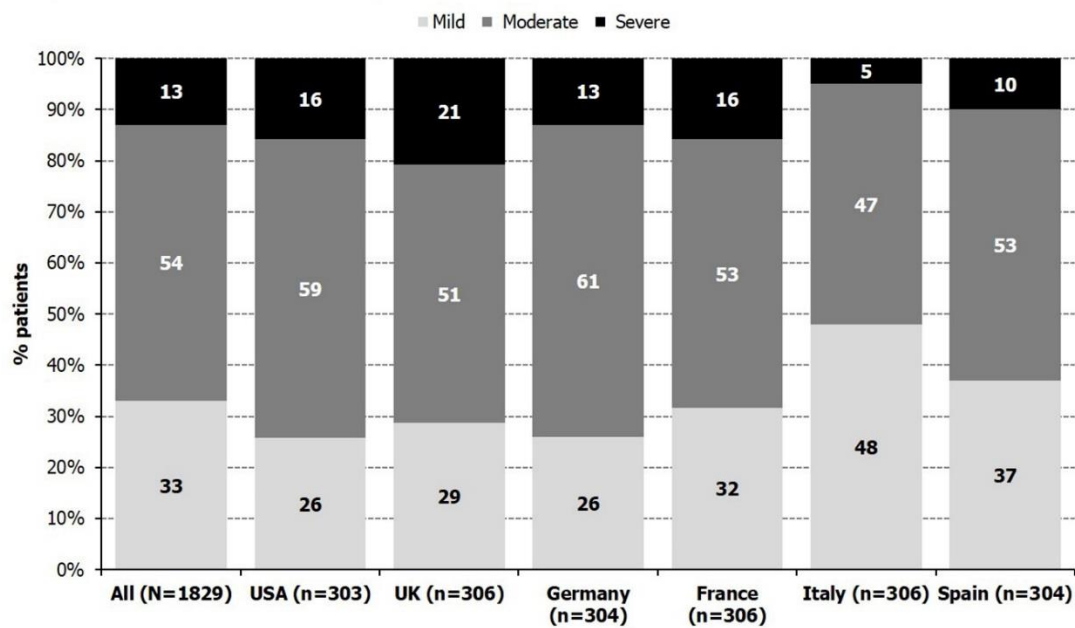
ONLINE SUPPLEMENTARY FIGURES

Supplementary Figure 1: RA disease severity in the survey populations

Good Days Fast survey



Getting To Your Destination Faster survey



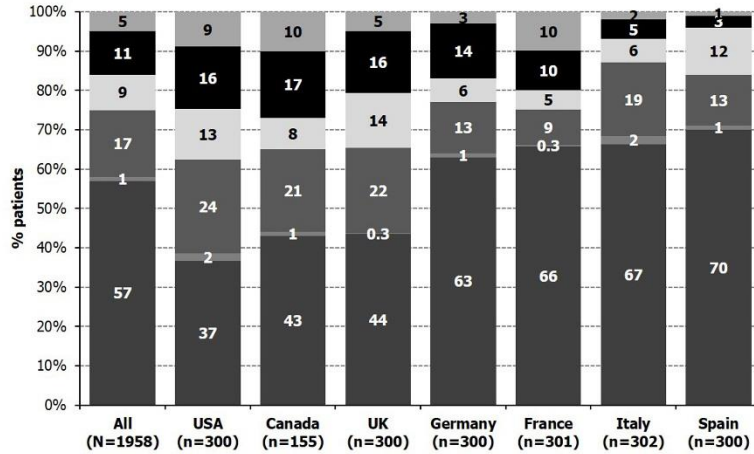
RA: rheumatoid arthritis.

Supplementary Figure 2: Employment status and work productivity of survey participants by country

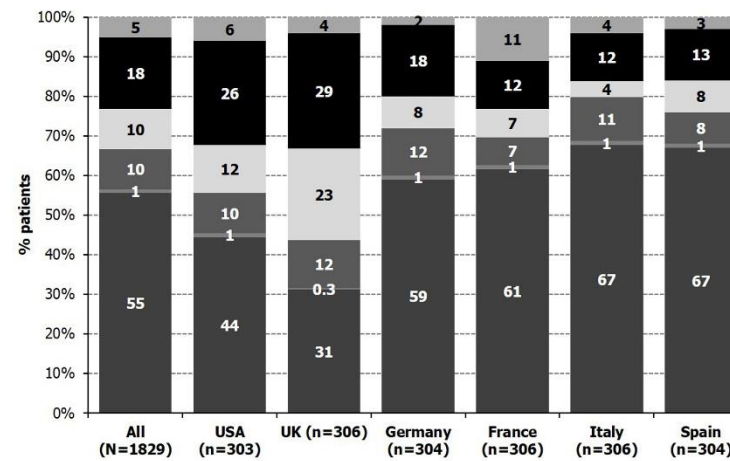
A) Employment status

■ Employed ■ Full time education ■ Homemaker ■ Unemployed/receiving benefits ■ Retired ■ Other

Good Days Fast survey



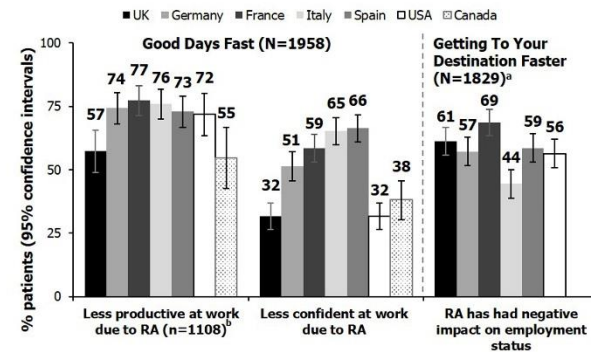
Getting To Your Destination Faster survey



B) Work arrangements affected by RA (Good Days Fast survey; N=1958)

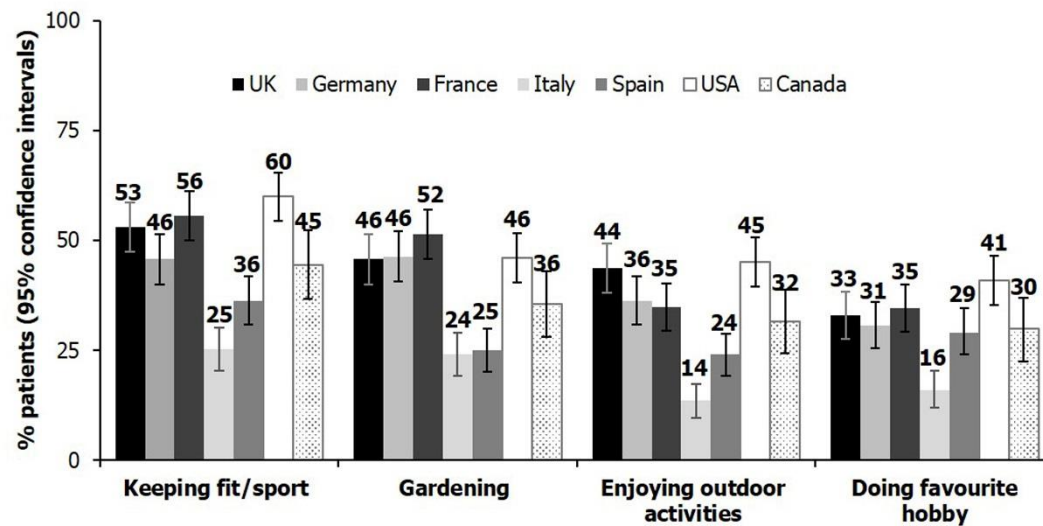
	% patients (95% confidence interval)						
	UK	France	Germany	Italy	Spain	USA	Canada
Stop working/retire early	33 (28, 38)	21 (16, 26)	19 (15, 23)	7 (4, 9)	9 (6, 12)	42 (36, 47)	36 (29, 44)
Work part-time instead of full-time	14 (10, 18)	17 (13, 21)	21 (16, 26)	15 (11, 19)	19 (15, 24)	13 (9, 16)	18 (12, 24)
Medical appointments during work time	20 (15, 24)	14 (10, 18)	20 (16, 25)	17 (13, 22)	43 (37, 48)	18 (13, 22)	19 (13, 26)
Changed type of work	13 (10, 17)	25 (20, 30)	14 (10, 18)	12 (8, 15)	21 (16, 25)	14 (10, 18)	16 (10, 22)
Take >10 days sick off work/year	13 (9, 17)	26 (21, 31)	31 (25, 36)	25 (20, 30)	31 (26, 37)	13 (9, 17)	12 (7, 17)
Workstation/environment modified	11 (7, 14)	16 (12, 20)	12 (8, 16)	12 (8, 16)	15 (11, 19)	8 (5, 11)	8 (4, 13)
Resist career advancement	7 (4, 10)	12 (8, 15)	13 (9, 17)	7 (4, 10)	10 (7, 13)	6 (3, 8)	9 (5, 14)
Take a pay cut	4 (2, 7)	5 (3, 8)	15 (11, 19)	6 (3, 9)	11 (7, 14)	5 (3, 8)	5 (2, 9)
Inform work about your condition	27 (22, 32)	34 (28, 39)	24 (19, 29)	23 (18, 28)	27 (22, 32)	22 (17, 26)	27 (20, 33)
None of the above	30 (25, 35)	19 (14, 23)	28 (23, 33)	35 (29, 40)	16 (12, 20)	29 (24, 35)	28 (21, 36)

C) Work productivity and self-confidence at work affected by RA



^aFor example, stopped working altogether, moved from full-time to part-time work, forced to change job or job role; ^bEmployed/self-employed: UK, n=131; Germany, n=190; France, n=198; Italy, n=203; Spain, n=210; USA, n=110; Canada, n=66

Supplementary Figure 3: Examples for activities frequently reported by patients to be compromised by RA by country (Good Days Fast survey; N=1958)



RA: rheumatoid arthritis.